

Co-Chairs Senator Abrams, Representative Steinberg, Vice Chairs Senators Anwar and Kushner, and Representative Gilchrest and other members of the Public Health Committee,

I am Taylor Biniarz and I am from Ellington. I am supporting **HB5303: An Act Concerning Continuing Medical Education Requirements Concerning Endometriosis and Cultural Competency and the Creation of a Plan for an Endometriosis Data and Biorepository Program.**

I am going to go into my personal experience with endometriosis but I would like to point out that as we know Black womens pain is less likely to be believed, diagnosed and treated properly and that includes when it comes to endometriosis and that also not just women have periods and endometriosis this is an issue trans men and those who are nonbinary face as well, and they often may face a stigma trying to get a diagnosis as well. This bill is extremely important because one of the main reasons our pain is not believed is because of the lack of training and the history of not believing pain for those of us with uteruses.

Endometriosis is not one size fits all, every person has a different experience with it even in slight ways. I probably started having symptoms as a late teenager but assumed they were normal period symptoms, and as someone who was on birth control as a teenager that probably helped to treat those early symptoms but at the same time mask them. At around 19 years old my pain started pushing past what I had deemed normal. Several nights a week I was up for hours in extreme pain often throwing up just from the pain, yet I still did not speak up, some people just have bad periods. After 2 years of just living in pain, having it affect my mental and physical health it all came to a head. The end of December in 2017 when I was 21, I woke up at 1am in this extreme pain and spent the night sitting, because laying down hurt even more, on the bathroom floor not being able to sleep, and throwing up several times from the pain. I was visiting family and my mother worked for a company that has an endometriosis product, and she also has endometriosis and has treated hers with a hysterectomy at this point.

At around 7am I knew she would be awake so I texted her to please come here and I started crying. I was in just so much pain and was also exhausted. I was told I was probably constipated and just needed to eat some ruffage. I walked hunched over to my aunts around noon and was given a light cramping med, a soft laxative and an apple to munch on. None of these things helped. At around 5pm I walked out very emotional and said I think I need to go to urgent care - and was told to stop crying so that I was not being taken anywhere if I was crying. The urgent care on the phone said that given where I was in pain that they would not take me in, that I would need to go to the emergency room.

Once I was taken back I was alone the entire time and while my doctor was extremely nice there was not talk of periods nor the mention of endometriosis. My symptoms were treated which I believe I appreciated. Around 7pm I was pain free for the first time since 1am that morning pain free. But not really given a cause or a reason and when I was discharged and left, the next day my diet was questioned as the source of my pain.

A few weeks later I received a very emotional text from my mother stating that she thinks that I may have endometriosis and that she was so upset because she realized what so many doctors do to us, what her work was trying to prevent that she did that to her own daughter. I forgave her and I appreciated that so much and have no hard feelings towards that as so much of that was taught in society which is why proper training is so vital.

I had extreme privilege in several ways in this next part, firstly as a white woman, but she reached out to her previous coworkers in CT and asked if they had any really good OBGYN recommendations pertaining to Endometriosis. She sent me the one she thought was best and I made an appointment, fun fact she is the Doctor who is in the Endometriosis Working Group so I can verify that she is a really phenomenal doctor on this issue.

I went in to my appointment and we talked about the most recent flare up of my symptoms and just my past history on anything pertaining to this appointment.

What I am going to say next sounds contradicting, I am aware. I was told I probably had a lower stage of endometriosis, now you're going "but you have said you have it several times in this document!" and that's correct but the only way to confirm a diagnosis of endometriosis is through a surgery and that was not presented as an option at that exact moment for reasons I agree with, any surgery carries its own risks and if presented with that option I am not sure what I would have done.

I was given a treatment option to try out to see if it worked - taking my normal birth control pills but skipping the placebo week so I would not have a period anymore and then also a prescription of what the doctor in the ER had prescribed just in case I had any more nights of severe pain which was an anti-cramping medication and an anti nausea medication for the anti-cramping medication.

And luckily so far that has worked, I have had only nights every once in a while with pain and when I do I take the meds prescribed to treat it and I mark it in an app I use to make sure it's not happening often or to an unbearable level. And I am lucky for that, for so many of those with endometriosis that option does not work or wears off over time. I assume at some point it will stop working for me. And I am lucky to have a wonderful doctor who believed and believes me and will help me when that happens. As someone who has never wanted children I know I would push for a more permanent solution which is what I am going to talk about next.

The way our bodies our uteruses are policed is abysmal, the way there can be someone in extreme pain who does not want kids or does not want to have them in a way that would use their personal body, and wants to have a hysterectomy yet medical professionals and to an extent legislators tell them that they cannot because they do not have kids, and furthermore 1 kid of each gender and over the age of 35, and what if their "husband" they haven't met yet wants kids.

First off assuming someone wants a husband is leaving out the LGBTQIA+ community. Secondly, giving a male who doesn't exist in my life a say over what I can do with my own body has me wanting to express my anger with words I cannot put here. This is my body, and my very real pain and the fact "a partner" who isn't me has more say then I do should be shameful to any person who suggests it. To the kids point: people and especially women on this point are allowed to not want to have kids and to make permanent choices to prevent that from happening.

I urge committee members to support this bill to help those like me who struggle with endometriosis.

Thank you,  
Taylor Biniarz